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CENTRAL HEALTH SERVICES COUNCIL

REPORT OF THE SUB-COMMITTEE
ON THE
Medical Care of
Epileptics



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The Medical Care of Epileptics

INTRODUCTORY

1. At their meeting on 15th June, 1954, the Standing Medical Advisory Committee had before them a memorandum by the Ministry of Health suggesting that the time had come when the arrangements for the medical care of epileptics might usefully be reviewed and setting out some of the problems involved.

The Committee decided to set up a sub-committee with co-opted members with the following terms of reference :

"To review arrangements for the care of epileptics and to make recommendations."

The membership of the sub-committee is shown on the preceding page.

2. The secretary of the sub-committee was Mr. P. Benner, and our meetings have been attended by Dr. I. G. H. Wilson and Dr. A. L. Winner, of the Ministry of Health, and Dr. P. Henderson of the Ministry of Education.

3. We have held 9 meetings, and amongst the documents we have considered have been memoranda from the Ministry of Health, the Ministry of Education and the Ministry of Labour and National Service. We have also obtained a considerable volume of detailed information from many sources, including Regional Hospital Boards, epileptic colonies and hospitals, and Medical Officers of Health, and we are most grateful to them for their help.

4. In carrying out our work, we have interpreted our terms of reference fairly strictly. There is a very close connection between the medical and the socio-economic problems of epileptics, and consequently there must be a high degree of co-operation between the various services whose task it is to try to solve those problems. It is probably true to say that nearly everything which is done for epileptics in the fields of education, welfare and employment has its medical aspects; but we have confined our attention to those matters which seem to us to be primarily medical, for we understand that separate enquiries are going forward in other fields. We have particularly in mind the Committee of Enquiry on the Rehabilitation of Disabled Persons, under the Chairmanship of Lord Piercy; but we should like to mention also the report of the Minister's Advisory Council for the Welfare of Handicapped Persons on the special welfare needs of epileptics and spastics (issued in 1953 under cover of Circular 26/53*), which contained many valuable recommendations, upon the application of some of which we have made suggestions. It is, however, inevitable that the recommendations we have made should affect services for epileptics other than

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purely medical services; we make no apology for this, believing as we do that the closest contact and co-operation between all the services concerned with the well-being of epileptics is of vital importance.

DEFINITION OF EPILEPSY

5. We considered at the outset whether for the purposes of our enquiry a formal definition of epilepsy was necessary. At present, the term "epilepsy," as commonly used, conveys a general idea of episodic attacks affecting consciousness, movement, sensation or behaviour, which may or may not be caused by a discoverable lesion or functional disturbance in the brain. The precise content of meaning, however, is not, and cannot be expected to be, constant, since the term "epilepsy," which originated some 2,500 years ago, when it conveyed the single and unambiguous idea of a seizure, has altered in meaning with the great advances in our knowledge of the nature and causes of epileptiform attacks. Practice now varies between using the word "epilepsy" for describing all such attacks, including those the cause of which is susceptible to discovery and perhaps to eradication (e.g., some cases of cerebral tumour or brain injury)—so called "symptomatic" epilepsy, and defining epilepsy as a "thing in itself" and limiting the word to describe what is now more usually known as "idiopathic" or "cryptogenic" epilepsy.

6. The definition and classification of epilepsy varies with the feature which is given greatest prominence. It may, for instance, be (a) the clinical pattern of the attacks, giving rise to such terms as grand mal, petit mal, Jacksonian epilepsy; or (b) the anatomical site of the responsible lesion—e.g. temporal, sensory, motor, diencephalic; or (c) physiological disturbances—e.g. E.E.G. patterns or blood changes—anoxia, hypoglycaemia, uraemia, etc.; or (d) pathological changes—e.g. sclerosis, neoplasm, etc. It is clear that, as hitherto, advances in medical knowledge will steadily reduce the content of the words "idiopathic" and "cryptogenic."

7. We considered the possibility of adopting a two-fold definition; the first part would be academic and in strictly medical terms, and the second would be for the guidance of those who are dealing with the medical and social needs of epileptics and would be mainly concerned with describing the types of epileptics whose care presents the most serious problems. We decided, however, that there were very serious difficulties in the way of producing the first part of such a definition. If it were made too general—e.g., in terms of abnormal neuronal energy discharges—it would cover so many conditions as to have little taxonomic value; if, on the other hand, we attempted a definition by a description of the various clinical patterns of epilepsy, it might well prove impossible to produce a form of words which would include all forms of what is now regarded as epilepsy and would not at the same time apply also to conditions not regarded as epileptic.

8. It appears to us, however, that the problem of finding a formal definition is not of immediate practical importance. We have decided that the balance of advantage lies in continuing to describe by the word "epilepsy" all its forms,

however caused, since it is the existence of the "fits," particularly in their more serious forms, which gives rise to the problems which we have been asked to examine.

9. We suggest that the problem of epilepsy should be approached for practical purposes from the point of view of:

- (1) establishing the fact that the patient suffers from epileptic attacks and, if possible, diagnosing their cause;
- (2) investigating the nature, intensity, frequency, etc., of the attacks with a view to considering the medical and social consequences and taking the appropriate practical measures;
- (3) assessing any accompanying physical or mental disabilities.

10. We therefore decided as a first step to find a suitable method of classifying patients who suffer from epileptic attacks, since we hoped that this procedure would enable us to examine the needs of each class of patient and to consider what medical provision (in the widest sense) was needed to meet them. The classification which we have adopted is a fourfold one, as follows:

- (1) The patient whose epileptic attacks, with or without treatment, recur infrequently; who suffers from no other demonstrable disease in the brain or elsewhere; and who shows no significant intellectual defect or abnormality of behaviour.
- (2) The patient who, in addition to his epilepsy, suffers from significant intellectual defect and/or physical disability (e.g. cerebral palsy).
- (3) The patient with epilepsy who does not suffer from mental defect in the usual sense (i.e., who is not of low intelligence) but who has serious behaviour disorders which render normal life in society difficult or impossible.
- (4) The patient who suffers from very frequent epileptic attacks which are difficult or impossible to control by treatment.

SIZE OF THE PROBLEM

11. In their report, the Minister's Advisory Council on the Welfare of Handicapped Persons estimated that the incidence of epilepsy in this country was at least 2 per 1,000 of the population, adding that they thought it preferable to err on the low rather than on the high side. It is extremely difficult to make a satisfactory estimate of the total incidence, since the information upon which it must be based is at present inadequate.

12. The General Register Office's Study on General Practitioner Records (Studies on Medical and Population Subjects No. 7., 1953) states that in ten selected practices the number of epileptics was 109, giving an incidence of 4 per thousand practice population. But these practices represent a relatively small population, and there is some danger in generalising from the figures. This survey was carried out in 1951/2. We understand that continuation of the survey showed an incidence of 3.4 per thousand practice population in 1952/3 and of 3.8 in 1953/4; but since the figures for the two years were presumably made up from much the same patients, their value in confirming one another is doubtful. In addition, we understand that these figures would not include patients not seen

by their general practitioners in the course of the year, even though they might in fact sometimes suffer from epileptic attacks. In the light of this and such other evidence as is available, it appears to us that a figure of 2 per 1,000 is too low and that 4 per 1,000 of population is probably a better estimate of the total incidence. It is, however, only a rough approximation. One reason for this lies in the disinclination to regard a patient as epileptic if, for example, he has had only one or two epileptiform attacks over a long period or has been altogether free of them for some time—for a doctor will naturally be reluctant to stamp him as an epileptic unnecessarily. Another difficulty arises from the frequency with which epilepsy is associated with other disabilities; thus a patient whose main disability is mental defect but who also suffers from epilepsy may in practice be classified as a mental defective and not as an epileptic.

13. This estimate of total incidence is, however, of little value to those concerned with the planning of the medical and other services needed by sufferers from epilepsy, since it includes people whose symptoms are either so mild as to cause them virtually no inconvenience or else have been so successfully controlled by the general practitioner as to render possible a completely normal life. It would be of more value to know that proportions of epileptics fall into the 4 classes mentioned above, but there is unfortunately very little evidence bearing on this problem, and much of what there is is so subject to inaccuracy as to be of little value. Some of the statistical data which have come to our attention do, however, seem to be worth mentioning :

- (i) In 1950/51 the Ministry of Education made a survey of 355,000 school children (ineducable children are not the responsibility of the Ministry of Education and were therefore excluded) from which it appeared that the incidence of epilepsy in this special group of the population was about 1.2 per 1,000—1.1 in the parts of the Metropolitan area which were surveyed and 1.5 in the other areas, which were in East Anglia and the North of England. We understand that in some districts the incidence was as high as 2 per 1,000; and we have seen other figures, for Liverpool, indicating that the incidence of epilepsy amongst school children there was 2.64 per 1,000.
- (ii) A recent survey in Dundee indicates a incidence in the area of 1.67 per 1,000 children aged between 5 and 15*.
- (iii) Arising from the survey by the Ministry of Education, it seems likely that some 10 per cent. of all epileptics may fall into the third of the four classes mentioned above—i.e. that of epileptics with anti-social behaviour disorders. This conclusion must, however, be regarded with caution since factors other than epilepsy may have contributed to the behaviour problem.
- (iv) We understand that in Middlesbrough, 242 cases of epilepsy were, in 1954, known to the Health Department of the local health authority, representing an incidence of about 1.57 per 1,000 of population. (For the reasons mentioned above, the total incidence would certainly be appreciably greater than this).

* For fuller details see pages 6-11 of the Health Bulletin of the Chief Medical Officer of the Department of Health for Scotland, Vol. XIII, No. 1 (January, 1955).

14. While we should have liked to be able to quote figures showing the numbers of people likely to be comprised in each of the four classes mentioned above, we think it is very doubtful whether such figures, even if they could have been obtained, would in practice be of great value for planning purposes since the relative sizes of the four classes are likely to change—for instance, there is every hope that recent advances in the treatment of epilepsy will in the future significantly reduce the number of patients who suffer from uncontrolled epileptic attacks and the other disabilities which are consequential upon them. *We are, however, prepared to express the opinion, without reserve, that epilepsy is a sufficiently major problem to demand that special medical provision be made for dealing with it.*

THE PRESENT PROVISION FOR EPILEPTICS

15. Many services have a part to play in the general care of epileptics; amongst them are:

(1) Medical services—

- (a) hospital and specialist service;
- (b) general medical practitioner service;
- (c) local health authority services (maternity and child welfare, health visiting, care and after-care, etc.);
- (d) the school health service of the local education authority;

(2) the welfare service of the local authority;

(3) the education service of the local education authority and the youth employment service;

(4) the disablement resettlement officer service of the Ministry of Labour and National Service;

(5) services provided by non-statutory bodies (e.g., epileptic colonies, industrial medical services, British Epilepsy Association).

Of these services, the first two and the last are of most immediate concern in any consideration of the medical care of epileptics.

Hospital and specialist service

16. The Minister of Health provides this service under Part II of the National Health Service Act, 1946; it is administered by Regional Hospital Boards, Hospital Management Committees and Boards of Governors, who are his agents for this purpose. It is essentially a specialist service and offers diagnosis and treatment to in-patients and out-patients. There are in the National Health Service two hospitals (St. David's, Edmonton and St. Faith's, Brentwood) which concentrate on the care of in-patients suffering from epilepsy. Institutions outside the National Health Service are dealt with in a later paragraph.

General medical practitioner service

17. This service is provided under Part IV of the National Health Service Act, 1946, and is administered by Executive Councils. The general practitioner sees his patients in his surgery or at their homes (which may be taken to include most types of institutional accommodation other than hospitals providing a

specialist service under Part II of the Act). Thus anyone living in an epileptic colony is entitled to receive medical care from a general practitioner under the National Health Service.

Local health authority services

18. These services are provided under Part III of the National Health Service Act, 1946 by local health authorities (County Councils and County Borough Councils). The services are provided either directly or, less often, under arrangements made with a voluntary organisation by the authority. Amongst the services provided are :

- Care of mothers and young children.
- Health visiting.
- Home nursing.
- Domestic help.
- Prevention of illness, care and after-care.

19. This last is, perhaps, of particular interest in connection with epileptics. Section 28 of the Act enables local health authorities to make arrangements for the prevention of illness, the care of persons suffering from illness or mental defectiveness, or the after-care of such persons. The section has not been made mandatory by the Minister except in respect of persons suffering from tuberculosis, but nearly all authorities have in fact provided in their schemes for a general service under this section of the Act. In practice this service is mainly confined to the loan of nursing equipment for patients nursed at home and to the provision of recuperative holidays, but health visitors, mental health workers and home nurses are to some extent providing after-care as part of their functions.

20. Section 28 of the Act gives local health authorities general after-care etc. powers in respect of mental defectives living in the community. In addition, specific duties under the Mental Deficiency Acts, 1913 to 1938, are entrusted to them by Section 51 of the Act. These duties briefly are:

- (1) to ascertain what persons are mentally defective and subject to be dealt with under the Acts;
- (2) to provide supervision for defectives, or to ensure that they are placed under institutional care or under guardianship;
- (3) to provide training or occupation for those not in any institution.

Welfare services

21. These services are provided by local authorities (County Councils and County Borough Councils) under Part III of the National Assistance Act, 1948. They fall into two main divisions:

- (a) *Accommodation.* Section 21 of the Act requires local welfare authorities to provide residential accommodation for "persons who by reason of age, infirmity or any other circumstances are in need of care and attention which is not otherwise available to them"; this obligation may be fulfilled in whole or in part by means of arrangements with a voluntary

organisation providing such accommodation, e.g. epileptic colonies. There is power under section 21 for the local authority either themselves to provide, in the residential accommodation, health services other than hospital and specialist services, or to secure the provision by the local health authority under Part III of the National Health Service Act, 1946, of the like services as that authority can provide under that part of the Act for persons in their own homes. The local authority can use one of these methods for providing some of the necessary ancillary services and the other method for providing other ancillary services.

- (b) *Welfare services.* Section 29 of the Act empowers local authorities "to make arrangements for promoting the welfare of persons . . . who are blind, deaf or dumb, and other persons who are substantially and permanently handicapped by illness, injury or congenital deformity or such other disabilities as may be prescribed by the Minister". The section is obligatory only in respect of the blind; for handicapped persons other than the blind, partially sighted and deaf, schemes under the section have been submitted by about three out of every four local welfare authorities. The schemes cover such matters as general social welfare, the establishment of sheltered workshops and of hostels, home employment, social centres and holiday homes, help in consultation with the Ministry of Labour in finding employment and the maintenance of a register of disabled persons.

These functions may also be discharged through the medium of a voluntary organisation.

The epileptic colonies

22. There are eight epileptic colonies and homes, six of them run by voluntary bodies and two by local authorities. When the National Health Service came into being they were not regarded as providing hospital and specialist services and therefore, unlike the two epileptic hospitals referred to in paragraph 16 above, did not pass to the Minister of Health. The normal arrangement is for the colonies to provide general medical services for their patients and to turn to neighbouring hospitals for such specialist services as may be needed. The cost of maintaining a considerable proportion of the patients in the colonies administered by voluntary bodies is met by local welfare authorities under section 21 of the National Assistance Act, 1948 (see paragraph 21(a) above), and where appropriate by the Local Education Authority under the Education Act, 1944.

MEDICAL PROVISION NEEDED FOR ALL CLASSES OF EPILEPTICS

(i) General

23. In the past 20 years there have been major advances in the medical treatment of epilepsy and many firms are synthesising new chemicals with radicals known to have anti-convulsant effects. It is the usual practice for firms to have liaison with centres dealing with large numbers of epileptic patients so as to carry out therapeutic trials. It is essential in all such trials to take the necessary safeguards, including obtaining the consent of the patient, parent or guardian.

24. This is indeed a time when advances of the greatest importance are taking place in the diagnosis and treatment of epilepsy. We have in mind not merely the appearance of new and improved drugs, important as this is, but the development and application of new techniques in hospitals. The localisation of brain lesions has been made more accurate by radiography, including pneumography and angiography, by electro-encephalography and by electrical stimulation of the exposed brain ; and the advent of methods of combating infection, shock and haemorrhage, and improved methods of anaesthesia, have widened the field of surgical endeavour. As an example, we would instance the pioneer work being done on the relief of temporal lobe epilepsy and behaviour disorders by means of surgical treatment.

25. Broadly speaking, the medical services which should be available for all patients suffering from epileptic attacks are firstly, treatment under the general medical services from general practitioners, and secondly, specialist diagnosis and treatment in hospitals where necessary.

(ii) Present position

26. The present position does not appear to us to be altogether satisfactory. The evidence suggests that a few patients are having no treatment for their epilepsy and that others are merely taking routine doses of various drugs, sometimes first prescribed long ago and never reviewed. There seem to be three main reasons for this state of affairs:

- (1) An insufficient appreciation of the contribution which modern advances in diagnosis and treatment have made to the problem of epilepsy, and of the need for periodic review and assessment of these cases.
- (2) A good many patients tend to look on epileptic fits with indifference, to accept them resignedly as inevitable and not to realise that they might be controlled by medical care. It also not infrequently happens that patients neglect to take the drugs which have been prescribed for them, or fail to visit their doctors regularly and thereby obtain the continuous medical supervision which is essential for the successful control of epilepsy. It is clear, therefore, that it is necessary for a more intensive effort to be made to inform sufferers from epilepsy of the nature and significance of their disability and to encourage them to secure treatment and then to follow the medical advice they are given. This is a matter in which both general practitioners and hospitals can play an important part, as well as local authority workers and voluntary organisations.
- (3) In many parts of the country the facilities for the diagnosis and treatment of epilepsy in hospitals are not yet adequate and general practitioners are often unable to secure appropriate specialist advice in really difficult cases. We understand that in 1951 the Ministry urged Regional Hospital Boards to try to ensure that in every area there was at least one consultant who was prepared to take an active interest in epilepsy; but the evidence before us suggests that this has only been partly carried out and that there are still considerable areas where advice on the special problems of epilepsy is not available or where, if available, those concerned seem to be unaware of it.

(iii) *Future needs*

We suggest that the medical provision which should be made for all classes of epileptics is as follows:

(a) *General Practitioners*

27. General practitioners have an active interest in the problems of the epileptic and there should be readily available to them the necessary hospital and specialist services, which in our view are likely to be needed for the proper management of the majority of cases. But—and we attach particular importance to this—the general practitioner should continue to be responsible for the long term medical supervision of his patient. This is especially significant for the epileptic, since his condition may change rapidly as treatment proceeds. The epilepsy may respond to treatment or it may change in type; or the drug itself may give rise to toxic effects such as rashes, pyrexia and blood changes; or it may induce lethargy or confusion. For these and other reasons, the dose of drugs must be constantly under review.

28. While we suggest that this most important function of continuing medical supervision should normally be the responsibility of the general practitioner, he should, of course, exercise it in conjunction with the hospital, if the patient has attended one, and with the School Medical Officer; and he should be informed of any action taken. And it might be found convenient for the consultant to arrange for the patient to see him at his clinic at regular intervals so that he can satisfy himself that the treatment being given is still suitable. The arrangements should be very similar to those suggested for diabetics in a memorandum* issued by the Ministry of Health in 1953. In brief, it proposed that there should be a number of suitably located specialist diabetic clinics, with beds as necessary, which patients could attend for initial assessment and stabilisation. Subsequently the patient would be under the care of his general practitioner, but would return to the clinic at intervals for review.

(b) *Hospitals*

29. The responsibility of the hospital service is threefold and, broadly speaking, is as follows:

- (1) to establish a complete diagnosis of the epilepsy and associated disabilities;
- (2) to advise on or initiate or carry out the necessary treatment, including rehabilitation;
- (3) with the general practitioner to assess and advise the patient and his family, in co-operation with the other services concerned, how best to solve the many problems to which his disability gives rise so that he may live as normal a life as possible amongst his fellows.

30. The first responsibility of the hospitals is to provide fully equipped diagnostic clinics where patients suffering from epilepsy can be fully investigated and treated. Patients attending such clinics may frequently be able to do so as out-patients; but in some cases, depending on the nature of the investigation

* Memorandum RHB(53)66/HMC(53)62/BG(53)64.

found necessary or on practical factors such as distance, this may not be possible. The clinics should, therefore, have associated with them a number of beds for those who have to be admitted as in-patients.

31. Their second responsibility is to provide beds (which might or might not be in the same premises as the diagnostic clinics) for all those patients who upon investigation are found to need admission to hospital for stabilisation of treatment. Stay in such treatment centres would normally be comparatively short, since we should expect that in most cases stabilisation could be achieved in at most two or three months. It would, however, probably also be necessary for there to be a small number of longer stay centres which could be used for the treatment and rehabilitation of the more difficult and resistant cases.

32. These hospital diagnostic clinics and treatment centres should normally be under the direct supervision of a neurological physician; but he is essentially the leader of a team consisting of paediatricians, psychiatrists, child guidance experts, radiologists, almoners, psychologists and others. Electroencephalographic facilities must also be available, and it is clearly preferable that the services of a neurosurgeon, both for certain diagnostic procedures and for operation, should be available in or close to the centre. In short, the selected hospital centre would have to be able to offer the services of almost all the specialties and ancillary services. From the evidence presented to us, we have no doubt that, when such clinics were established, the necessary staff could be found.

33. We recommend, therefore, that, for the epileptic, hospital authorities should be encouraged to establish, on a regional basis, diagnostic and treatment clinics and longer-stay treatment and rehabilitation centres. The detailed arrangements will clearly have to be decided in each region according to its geography and present resources, but the general pattern should conform to that which we have indicated. It has been argued that there is an insufficient demand to justify development along these lines; the evidence available suggests that there is in fact a considerable potential demand and that the patients will be forthcoming once the facilities are available. We believe that this is a field where a very great deal of good can be done by a comparatively small-scale service in the first place; and experience proves that where this service is available, an appreciable number of patients can be saved from life-long disablement.

34. It is evident that in establishing the hospital services we have recommended, Regional Hospital Boards and Boards of Governors will have to work together closely. We would also urge most strongly that hospital authorities should regard it as part of their duties to enlist the co-operation of general practitioners by making the service known to them and to encourage them to refer suitable cases to the centres; for only through the help of the general practitioner can hospital treatment be made available to all those who need it. Co-operation with the general practitioner should, of course, as we have already indicated, extend to the period after the patient has been discharged from hospital.

35. We can make only tentative suggestions about the scale upon which these facilities should be provided. We have mentioned in paragraph 32 the services which should be available at any hospital centre concerned with the diagnosis and treatment of epilepsy; and the availability in one place of so wide a range of

staff and services will necessarily limit fairly strictly the number of centres where such units can be provided. The ideal number of units cannot be accurately estimated in the absence of definite information about the incidence of epilepsy either in total or in its various types, and it will therefore be necessary to proceed gradually, on an experimental basis, by trying to match the scale of services to the need, bearing in mind that at present the demand is to some extent potential. We suggest, however, that each Regional Hospital Board might aim at establishing in the first place one diagnostic and treatment clinic for each million of its population, and one long-term treatment and rehabilitation centre for each two millions of its population.

36. *Epilepsy with behaviour problems.* In addition to these general recommendations about hospital services for epileptics, we wish to refer particularly to the need for investigatory clinics for epileptics with behaviour problems. This is a particularly difficult class of patient and there is a danger of deterioration, perhaps irreversible, unless suitable action is taken at an early stage—say, during adolescence. It may, therefore, be useful if we describe in some detail the services which we think would be required by such patients; and this will have the additional advantage of illustrating the factors which may to some extent affect all classes of epileptics and the hospital facilities which are likely to be needed.

37. The factors which may contribute to the development of behaviour disorder in this class of patient are frequently diverse, and include poor parental attitudes, disturbed homes, noxious environmental circumstances outside the home, educational retardation, mental defect, specific learning defect, emotional disorder (the latter perhaps consequent upon sub-clinical seizures) and temporal lobe lesions. The investigation therefore necessitates studies made from many different aspects—psychiatric, neurological, social, psychological, electroencephalographic and often neuro-radiological. The ideal situation, therefore, for an investigatory clinic of this type is a hospital centre where workers in all these fields are to be found together. It should also be borne in mind that the majority of the patients will not be confined to bed and that recreation rooms and occupational facilities will therefore also be necessary. We believe that the orientation of a clinic of this particular type should be primarily psychiatric rather than neurological, and that its day to day work should be under psychiatric supervision. In fact, frequency of seizures seems only rarely to be a main cause of behaviour problems.

38. It is probable that a significant proportion of epileptic patients showing behaviour disorders will prove to be suffering from temporal lobe epilepsy, since we are informed that psychological disorder seems to be an intrinsic part of about 50 per cent. of the cases of temporal lobe epilepsy. The part which surgery will play in the treatment of this condition will be more clearly defined during the next few years when its long-term results can be ascertained, but it is clear that more provision will be needed for this group. In our view, therefore, investigatory clinics of this nature should be situated in centres where facilities for expert neurosurgical treatment are readily available.

39. If it is to be an economic proposition, the investigatory unit should have at its disposal 30 to 50 beds to which patients can be admitted either for special investigation lasting two or three weeks or for more prolonged observation and

treatment lasting three or four months. The best use of the unit will be made if there is a very active out-patient clinic and follow-up system. We gather from the experience of the Maudsley Hospital that a 50 bed unit could handle about 200 patients per year, including stabilisation by drugs and rehabilitation after surgery. These patients require on the average three to four months' treatment. The full-time staff of the unit might include a consultant psychiatrist, two psychiatrists of registrar grade, a clinical psychologist and a psychiatric social worker. There should be an active E.E.G. department readily available and also facilities for neuroradiology; and the services of consultants in neurology, neurosurgery, general medicine and paediatrics would be essential. It is difficult at present to assess the likely demand for this type of unit, but we would recommend that as a first step three or four additional units of the Maudsley type be established at convenient geographical centres in this country.

40. *Socio-economic problems.* The third responsibility of hospitals, which arises when diagnosis and treatment have been completed, is to play their part with the family Doctor in helping to deal with the socio-economic problems with which the patient may be faced and to give advice on the mode of life which will be most suitable and which will best enable him to live with such disabilities as may still remain. At this point we wish to stress that the interest of doctors—consultants and general practitioners alike—should extend beyond the mere diagnosis and treatment of epilepsy and that they have an essential part to play in co-operating with the various agencies whose task it is to help the patient to find a suitable place for himself in the world and to lead as normal a life as possible.

41. Often it may be possible for a patient to return to a normal or almost normal life, and in such cases all that may be needed will be simple advice from the consultant—e.g. that certain types of work should be avoided (near moving machinery, for instance, or at a height). In other cases, it may be found that the epilepsy or associated disabilities cannot be adequately controlled and are so disabling that some form of long-term care (e.g. in an epileptic colony) is necessary; this decision is most often primarily a medical one. In still others, resettlement in the community, though possible, will present difficulties: assistance from the domiciliary services of the local health and welfare authorities may be required, or the help of the disablement resettlement officer may be needed for finding suitable employment (a matter which we refer to in greater detail in paragraphs 66-71). In all these cases it is very important that the extent of the patient's disabilities and capabilities should be accurately known, and this is obviously a field where medical advice is essential. In this connection we would strongly commend the recommendation made in a recent hospital memorandum issued by the Ministry of Health* that hospitals should seriously consider establishing resettlement clinics—i.e., informal meetings at which, for any patient who on his discharge is likely to experience difficulty in re-establishing himself in society, the consultant in charge of the case, the almoner, the disablement resettlement officer, representatives of the local health and welfare authority services and anyone else who may be concerned can consider the case in detail and by a full exchange of information try to find a solution to the patient's problems. *We recommend that all diagnostic treatment and rehabilitation centres for epileptics should be encouraged to make arrangements on these lines for close*

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liaison with all the other services which are concerned in dealing with the socio-economic problems of the sufferer from epilepsy.

SPECIAL PROVISION FOR EPILEPTICS

Treatment of Physical disabilities

42. Appropriate treatment will be needed for any physical disabilities which are present in addition to the epilepsy. Where the treatment is given will largely depend on the nature of the physical defect and whether it or the epilepsy is the major disability.

Education

43. It may be helpful if at this stage we refer briefly to the statutory position regarding the education of children with epilepsy, and to the policy of the Ministry of Education.

(a) *Education Act, 1944.* Section 8(2) made it the duty of every local education authority to secure that provision is made for pupils suffering from any disability of mind or body by providing, either in special schools or otherwise, special educational treatment.

Section 33 gave the Minister of Education the duty of making regulations defining the several categories of pupils requiring special educational treatment and making provision as to the special methods appropriate for the education of pupils of each category. Epilepsy was one of the categories defined. Section 33 also required local education authorities to arrange so far as is practicable for the special educational treatment of handicapped pupils whose disability is serious in special schools appropriate for that category.

Section 34 gave local education authorities the duty to ascertain which children in their areas over the age of two years require special educational treatment and to provide it. A local education authority, however, cannot attempt to enforce school attendance until a child is five years old.

Section 38 stated that a registered pupil at a special school was "deemed to be of compulsory school age until he attained the age of sixteen years."

Section 48(3) (as amended by subsequent enactments) gave local education authorities the duty to secure that comprehensive facilities for free medical treatment, other than domiciliary treatment, either under this Act or otherwise, are available for pupils attending maintained schools.

Section 48(4) gave local education authorities the duty to make arrangements for "encouraging and assisting pupils to take advantage of these facilities" except in cases where parents objected.

Section 56 gave local education authorities power to make special arrangements for the education of children or young persons "otherwise than in school" if there were "extraordinary circumstances" that prevented a child or young person attending a suitable school. It has seldom been necessary, however, to resort to this Section of the 1944 Act for arranging for the education of epileptic children since practically all of them can be educated in ordinary or special schools.

(b) *The School Health Service and Handicapped Pupils Regulations, 1953.* Regulation 14 defined epileptic pupils as "pupils who by reason of epilepsy cannot be educated under the normal regime of ordinary schools without detriment to themselves or other pupils". In the 1945 Regulations, the definition was narrower and implied that epileptic children could not be educated in an ordinary school.

Regulation 15 prescribed that a handicapped pupil, if not blind or deaf, should be educated in a special school or in an ordinary school as may be appropriate in his case.

(c) *Policy of the Minister of Education on boarding special schools.* The following important statement was made in Circular 276, issued on 25th June, 1954:

"The Minister wishes to take this opportunity of emphasising that boarding special schools and homes should be reserved for those cases where there is no satisfactory alternative solution—either because the nature of the handicap or the home conditions are such that boarding is an essential part of the special educational treatment, or because there is no day special school within reach. Apart from any question of expense, in other cases it will usually be in the child's interests to remain in his own home. No handicapped pupil should be sent to a special school who can be satisfactorily educated in an ordinary school. Where a special school is necessary, a day school is preferable if it offers a satisfactory and practicable solution".

44. A number of questions relating to the education of children suffering from epilepsy were touched on in the report of the Minister's Advisory Council on the Welfare of Handicapped Persons, to which we have already referred. Paragraphs 8 to 13 of that report are relevant and are as follows:

"8. The Committee received evidence which indicated that of the estimated number of epileptic children needing special school facilities something over one-third were so accommodated at the present time, and it was thought that very few of these would benefit from higher education. (Information received more recently shows that at least two-thirds of the epileptic children who need a special school education are now in such schools.) It was alleged that a number of epileptic children who are unsuitable on account of low I.Q. or behaviour difficulties are admitted to these special schools, and there is difficulty in getting local authorities to remove them as no alternative accommodation is available. The evidence indicated a certain absence of guidance from school-leaving age through adolescence into employment. This point is developed below.

9. It is desirable that local authorities should be aware of epileptic children before they are ready for school, and every step should be taken to ensure that the School Medical Officer is informed of epileptic children as soon as possible after they are two years old. Admittedly the ascertainment of epilepsy in the first four years of life is complicated by the higher incidence of convulsions of all kinds during these years (and this also occurs at puberty), but an American survey shows that the incidence of convulsions in infancy is five times greater in epileptic than in unselected children and that among epileptic children those with a family history of epilepsy show eight times as many convulsions in infancy as

those without such a history. On the other hand care should be taken not to "label" a child as an epileptic without first subjecting him to a period of observation.

10. The Committee considers that general practitioners should be asked to bring to the notice of the School Medical Officer all epileptic children and children suspected of having epilepsy. Where doubt exists about the diagnosis the diagnostic facilities provided at hospitals should be utilised, and these should be regarded in such cases as an additional weapon to assist those who are carrying out the statutory duty to ascertain the epileptic and handicapped child. It would probably be an advantage for each epileptic child to be seen at a diagnostic department at least once.

11. The Committee believes that it is of the utmost importance that an attempt should be made at the outset to determine the child's educability and that he should be dealt with on the following lines:

- (i) there should be early ascertainment of all epileptic children for special educational purposes, and where it is clear that their handicap is of a permanent and substantial character, for welfare purposes: in any event the application to the case of the care and after-care services of the National Health Service should be considered;
- (ii) there should be continuous and close liaison between all officers functioning under the various services; arrangements should be made for periodical examination and, when necessary, re-classification of epileptic school children so that their transfer to the appropriate school may be achieved as early as possible;
- (iii) where an epileptic child returns home from a residential school for any length of time it is desirable that contact with the child and his parents should be made by the appropriate officer of the local authority.

12. The re-assessment of epileptic children at school leaving age, with particular regard to the severity of the disability and to employability, is most important. The School Medical Officer is responsible for securing that this is done and if necessary could be assisted in making such re-assessment by the advice of the diagnostic department of a hospital. In this work, he will need to co-operate closely with the youth employment officer and it is suggested that at this point officers of the local authority welfare and health departments should be consulted. In the case of children leaving colonies the present practice whereby the medical superintendent makes an assessment of the child's capacity is of the greatest value and should be continued; his report should be sent to the School Medical Officer of the authority; suggestions are made in paragraph 26 below, in regard to adolescents entering the employment field.

13. The Committee has made certain suggestions which will be submitted to the Minister of Education for her consideration; these include the need for continued effort to ensure that whenever possible the epileptic child is educated in the ordinary school in spite of any slight

inconvenience he may cause, the possibility of creating additional places at existing special schools and the desirability of establishing one or two national special schools for epileptic children with other handicaps."

45. We found ourselves in general agreement with the conclusions reached by the Advisory Council, but thought that certain points required a slightly different emphasis. Our general conclusions—which relate also to a number of points outside the field of the Advisory Council—are as follows:

- (i) It should be the aim of all concerned to ensure that children suffering from epilepsy are, wherever possible, educated in ordinary schools. We understand that this is in fact the policy of the Ministry of Education, and that about 80% of children with epilepsy are at present so educated. In this connection, we would stress the importance of making teachers aware of the significance of epilepsy. Experience shows that when this is done the teacher treats the attack with equanimity and the pupils accept the situation without fear or alarm.
- (ii) The Advisory Council recommended in their report that the greatest care should be exercised before "labelling" children as epileptics. In this we fully concur, and would emphasise its importance. We suggest that a child should be treated as epileptic only when the condition has been diagnosed beyond all reasonable doubt; and this will in many, and probably most, cases mean that the child should have been investigated fully at a diagnostic centre at a hospital. Cases have come to our notice where a child who has not had a fit for many years has continued to be regarded as an epileptic. We would urge that these cases should be regularly reviewed and that if a child remains free from fits after treatment has ceased for such a period as his medical advisers regard as adequate—this will naturally vary with the nature and severity of the fits—he should no longer be regarded as suffering from epilepsy, though he will continue to be under such medical supervision as may be deemed necessary (as described in paragraphs 27-28 above).
- (iii) The Advisory Council also recommended that steps should be taken to ensure that the school medical officer is informed about all children suffering from epilepsy as soon as possible after they are two years old (though the information available to us suggests that so far this recommendation has largely been ineffective). There appear to be two main reasons in favour of this course. The first is that it has been found in practice that about 20% of all children with epilepsy will at some time or another require places in special schools; if the total number of children with epilepsy is known, the local education authority can estimate how many places in special schools will be required. The second is that previous information enables the school medical officer to warn teachers in ordinary schools if any of the children coming into their classes are likely to suffer from occasional fits and to explain what measures should be taken to deal with them. We understand that a great deal of valuable work is being done in educating teachers in this way, but that much of it is liable to be undone if a child has a fit in class unexpectedly; and the result of this might well be the child's exclusion from school and the loss of a proper education.

We are in agreement with the intention underlying the Council's recommendation, but we are not satisfied that it is in practice necessary for the School Medical Officer to be informed about all children with epilepsy at so early a stage; and if this can be avoided, it should be, in view of the danger of wrongful "labelling". In our view the local education authority would have sufficient information to be able to ensure that adequate facilities were available for special education if the children were assessed thoroughly at the age of, say, four at a hospital diagnostic clinic and the School Medical Officer were informed only of those who then appeared likely to require special educational facilities. The responsibility for arranging this assessment would lie with the general practitioner and hospital clinic concerned. This method has the advantage that the decisions whether the child should be treated as an epileptic and, if so, whether he would have to attend a special school, would be put off as long as possible, so that wrongful "labelling" would be much more unlikely. It is true that it might not always be possible to assess accurately a child's educational needs at this stage. We are, however, advised that there would probably be difficulty in assessment in only about 25% of all cases at the present time, and that this proportion would almost certainly decrease very considerably as more experience of this type of work was gained. We therefore feel justified in recommending that this procedure should be generally adopted.

In addition, we recommend that the general practitioner should inform and consult with the School Medical Officer about any child suffering from epilepsy who is about to attain school age and is to attend an ordinary school. The School Medical Officer can then give the necessary instructions to the teacher of the class which the child will be entering.

- (iv) Experience shows that some 20% of children with epilepsy cannot at present, because of their disability, be educated in ordinary schools. Of this group, those who are educable will have to attend special schools, though every effort should be made to return them to ordinary schools as soon as possible. Owing to the relatively small number of children with epilepsy the special schools which provide for their needs have normally to be residential and they are in fact in most cases associated with an epileptic colony. This is, in our view, desirable inasmuch as association with the colony should ensure that continuous medical supervision will be available. It is, however, most undesirable that the children should be housed in proximity to deteriorated adults, so that they or their parents receive a misleading impression of their likely future. We therefore recommend that, when a school is associated with a colony, it should as far as possible be kept completely separate from the rest of the colony.
- (v) When the question of arranging for a child with epilepsy to attend a special school is under consideration, it is important to remember that such children not infrequently suffer from some specific defect—e.g. word blindness—so that they are very backward in one respect though of normal, or perhaps high, intelligence in others. In our view it is desirable that the services of an educational psychologist should be available so as to ensure that this defect is recognised and the child receives appropriate

treatment and is not merely regarded as backward. In this connection we are glad to learn that the Ministry of Education is encouraging the establishment of a school psychological service. One method of utilising the services of educational psychologists would be to associate them with diagnostic clinics at hospitals, at which the children would receive a full psychometric investigation when they attended for diagnosis in the first place and to which teachers in special schools could refer individual children as necessary. In our view, however, it would probably be preferable for the psychologist to spend considerable time in the school itself, so that he could observe the children in their normal environment. Thus it might well be suitable for a psychologist to be on the staff of an epileptic colony as a whole, with the care of the children as only a part of his duties. Alternatively, a large school might justify a whole-time appointment or one psychologist could, perhaps, look after a number of smaller schools.

- (vi) There remains the problem of the small number of children who, in addition to their epilepsy, suffer from behaviour disorders so bad that the special schools are unable to take them. A number of such children are known at the moment to be in mental and mental deficiency hospitals, though they are not necessarily of low intelligence. In some cases medical or psychiatric treatment at a hospital out-patient clinic will make it possible for the child to attend a special or an ordinary school, but a residue of especially difficult cases would still remain. For these children it has been suggested that there is a case for establishing one or two long-stay hospital units with full facilities for psychiatric treatment (in addition of course to the treatment needed specifically for the epilepsy). Since such units would be comparatively long-stay, educational facilities would also be needed; but the units would primarily be therapeutic and their ultimate object would be to return the children to ordinary or special schools. In our view this is an experiment which the Ministry of Health, in consultation if necessary with the Ministry of Education, might profitably undertake.

Long-stay provision

46. At present there are an appreciable number of epileptics in long-stay accommodation, particularly in the epileptic colonies. We do not consider that the number now in such accommodation is any indication of the amount of accommodation which may be required in future, for two main reasons:

- (a) Recent advances in medical knowledge offer a much greater hope than previously that epilepsy can be controlled or cured; and there is no reason for supposing that these advances will not continue.
- (b) Many remediable cases of epilepsy have in the past been allowed to become chronic either because adequate medical services were not available or because for various reasons the patient has not taken advantage of them. We hope that our report may in some degree help to end this state of affairs, and to improve those services.

47. It is nevertheless true that there will be a number of patients, though we hope a reduced number, who, after medicine and surgery have done all they

can, will still be too seriously disabled by their epilepsy or by associated disabilities to live a normal life in society and who will therefore require long-term institutional care. The types of institution most likely to be concerned are epileptic colonies and hospitals, mental and mental deficiency hospitals, and chronic sick hospitals. The choice of institution is of importance to the welfare of the patient and in our view the first step should be to determine which is the patient's major disability so that he can be placed accordingly. A patient whose main disability is mental defect but who has occasional fits should enter, not an epileptic colony, but a mental deficiency hospital, where he can receive the type of care he most requires. The task of the colonies should be to rehabilitate and care for those whose main disability is epilepsy; they should not be burdened with what are essentially the functions of mental and mental deficiency hospitals. We gather from the reports we have received that there are now some patients in colonies who could more suitably be in other types of institution, and that the reverse is also true. This state of affairs could be ended in the long run by a more careful choice of institution in the first place (this is to a large extent the responsibility of the hospital service—see paragraphs 40-41 above); but it would be useful if an interchange of existing patients could be arranged now so as to secure a more satisfactory classification.

With these prefatory general remarks we turn to a more detailed consideration of certain types of long-stay accommodation.

(a) Mental and mental deficiency hospitals

48. Mental defect is not infrequently associated with epilepsy and in a number of cases is the major disability. Patients who, owing to their mental disability, have to enter a mental or mental deficiency hospital should, of course, also receive the appropriate treatment for their epilepsy. We understand that these hospitals find that patients with epilepsy tend to be troublesome; and it would appear that one cause of this—and indeed of apparent mental defect—may be the patient's inability to adjust himself emotionally to his epilepsy. This is a point which should in our view be borne in mind by all those concerned in the diagnosis and treatment of epilepsy, and illustrates the importance of psychiatric advice being available at all hospitals concerned with epilepsy.

49. One of the problems to which our attention has particularly been drawn is that of the aggressive anti-social epileptic, who frequently does not seem to fit into any of the types of accommodation provided by hospital or welfare authorities. Part of the difficulty is that at present it may often be impossible for such patients to be admitted to or retained in mental and mental deficiency hospitals under compulsory powers. We are, however, aware that evidence on this subject has been given to the Royal Commission on the law relating to mental illness and mental deficiency.

50. In any event, the aggressive epileptic of this type should in our view often be classed as a psychopathic personality rather than as primarily epileptic; and though the epileptic psychopath is frequently very difficult to deal with, it seems doubtful whether he presents unique problems or whether arrangements should be made for his treatment over and above those which we have recommended for epileptics and those which are, we understand, being made to a slowly increasing extent for psychopaths. We set out in the paragraph below the general considerations which have led us to this conclusion.

51. Experience shows that the patient suffering from both psychopathy and epilepsy frequently has disease of or damage to the brain. In the case of younger patients especially, surgical intervention may be possible and offers hopes of ameliorating or removing both types of symptom. Where the patient is older, surgical intervention offers less hope of benefit. But if the diagnostic and treatment facilities which we have recommended in earlier paragraphs were adequate to deal with all cases, it would be reasonable to assume that the great majority of patients suffering from epilepsy, with or without other disabilities, would be detected early and would receive all possible treatment for their epilepsy. If after this had been carried out there remained as the dominant disability a psychopathy, the patient would be cared for under whatever arrangements had been made for psychopaths generally.

(b) The Epileptic Colonies

52. All the larger epileptic colonies were founded between 1888 and 1906 to provide a permanent shelter or retreat for the epileptic, and the word "colony" was chosen to indicate that in them lived a community, free and independent, but each member contributing according to his ability to the needs of the community. In many colonies the variety of patients is very wide, ranging from the epileptic of normal intelligence and good physique with well controlled attacks to the mentally defective, demented, psychotic and grossly abnormal behaviour types.

53. A great deal of very good work has been and is being done by the epileptic colonies and hospitals, but we are convinced that improvements could be made. We have already suggested that one of these would be to ensure that the colonies have only the type of patients they are best qualified to deal with—i.e., the patient whose main disability is epilepsy. There is ample evidence that many colonies have at present to care for many unsuitable cases. Moreover, in some colonies, buildings are unsatisfactory, patients have little privacy and the atmosphere is one of "institutionalism". Many colonies have difficulty in securing the numbers and type of staff they need. Finally, and most important, we think that in some of the colonies there is a misconception of the proper function of long-stay institutions for epileptics.

54. The functions of the colonies appear to us to be two-fold. In the past, a major duty has been custodial; they have aimed at providing a suitable environment for the epileptic who, after investigation and treatment at a hospital, has found himself unable to cope with life in the outside world. It seems to us, however, that the colonies have tended to concentrate too much on this aspect of their duties and to lose sight of the contribution they should make to rehabilitating the patient so that he may return to a useful and satisfying life amongst his fellows. In our view this should be their primary task for the future. In stressing this we are, of course, not breaking new ground but are recommending merely that epileptic colonies should play their part in one of the most encouraging recent advances in the socio-medical field—that of the rehabilitation of those suffering from chronic long-term disabilities. It is true that as improved medical services become available for epileptics and treatment is started earlier, there should be some decrease in the number of patients needing this type of rehabilitation. The evidence we have received leads us to believe that there are a considerable number of patients now in the colonies who could profit from properly directed rehabilitation. In addition, there may be a number of patients

receiving treatment in hospitals who, because of behaviour disorders or the stress of developing epilepsy or domestic difficulties, may need a longer period of rehabilitation than the hospital can conveniently provide before their social and economic problems can be solved or before their medical treatment can be stabilised; it is for such patients that the colonies will provide if our later recommendations are implemented.

55. The therapeutic, as distinct from the custodial, work of the colonies will then have two aspects:

- (a) *Medical care.* Most of the patients entering the colonies should previously have attended a hospital. The task of the colony will, therefore, be firstly, to provide for their day-to-day medical care, as they now do, which will, no doubt, be carried out by the medical staff acting, in effect, as their general practitioners; and secondly, to ensure that hospital specialist services are available as necessary. The latter implies close liaison between the colony and a suitable hospital centre, for some of the patients will need to be under constant specialist supervision if their rehabilitation is to be rapid and successful, and many will need reassessment at a hospital at fairly regular intervals.
- (b) *Rehabilitation.* Here the main need is to prevent the patient from becoming institutionalised and to stimulate his desire to return to normal life—in general, continued life in the colony should not be presented as the most desirable goal. A great deal depends on the atmosphere of the institution—e.g., upon the accommodation (whether home-like or institutional) and upon the general attitude of the staff towards the patients (whether they are treated as responsible people or not). Given the right background in these respects, we consider that the colonies should try to provide not simply occupational therapy but vocational training, or at least work which can be seen to have intrinsic interest and value; and the reward for good work should be the economic wage for the work done, as against pocket-money. We recognise that a considerable proportion of patients in colonies are severely disabled, but we are convinced that measures on these lines are of the first importance. At this stage we would again draw attention to what we have said about discharge arrangements in paragraphs 40-41 and employment problems in paragraphs 66-73, since this applies to colonies as well as to hospitals.

56. We have been told that payment of an economic wage to a patient by a colony may lead to difficulties. We are advised, however, that though difficulties would be likely to arise in the case of a person living in a hostel provided under Section 21 of the National Assistance Act, 1948, as being in need of care and attention, this would not be true of a hostel provided under Section 29 of the Act. At present there are very few such hostels, most of them provided by voluntary bodies. But we understand that there is no legal reason why at any rate part of an epileptic colony could not be reclassified as a Section 29 hostel; the patients living in it could engage in normal work provided for them as registered disabled persons under the Disabled Persons (Employment) Act, 1944, or they could be employed at a sheltered workshop in the colony or elsewhere. In this connection we understand that some hospitals and local authorities, instead of running

workshops, have been able to secure piece-work for their patients from industrial firms, who pay at normal rates. This possibility seems worth exploring further, though we gather that some of the colonies have in fact tried it unsuccessfully, apparently because so many of their patients are unable to do a normal day's work. This is, perhaps, because they have a high proportion of severely disabled epileptics, those less seriously affected being able to live in the community.

57. We have given a good deal of thought to the means whereby our views on the role of colonies in the management of epileptics might be put into effect. One conclusion is clear. If the best service is to be given to the epileptic, there must be (1) a closer functional link between the colonies and the resources of the National Health Service, and (2) a much greater emphasis on the rehabilitative functions of the colonies. One method of securing this administratively would be for the Minister of Health to promote legislation securing the incorporation of the colonies into the Service. In support of this course it is urged:

- (1) Functional integration would certainly be facilitated if all necessary diagnostic and therapeutic (including long-term) measures were directly available through one supervising authority, namely the Regional Hospital Board or Board of Governors; and the work of the colonies could be directed more easily to the fulfilment of a national plan.
- (2) The financial position of the colonies would be improved and the staff would enjoy the benefits of service in the National Health Service. (Against this, it might be said that if colonies charged higher fees to welfare authorities and were used by Hospital Boards for long-stay observation and stabilisation, their financial position would be improved, though this would be most unlikely to meet capital needs.)
- (3) In the junior grades especially, recruitment for the medical staff would be from a wider field if service in the colonies were regarded as part of post-graduate training (e.g. as registrars) within the National Health Service.
- (4) The colonies could more readily carry out the type of work in the field of education, training and social rehabilitation which is undertaken by the more progressive hospitals in the Service, e.g. in mental deficiency.
- (5) It would equate colony treatment with hospital treatment in regard to the making of charges for accommodation. At present, patients who are in colonies under arrangements made by local welfare authorities are required to contribute towards their maintenance in accordance with their means.

58. Amongst the reasons adduced for not taking the colonies into the National Health Service are:

- (1) That the Government is unlikely to take over the colonies without paying compensation and that the cost of this would be prohibitive. On the other hand, it is argued that in 1948 the Government took over the voluntary hospitals without compensation and the position of the colonies is analogous.
- (2) Colonies may be regarded as performing two functions. The first relates to those inmates whose stay is short and whose treatment is rehabilitation and care—essentially a hospital responsibility. The second covers the

custodial work of the colony and is concerned with the patients who remain for an indefinite time or permanently in the care of the colony. These patients form a "closed community" and it is suggested that their care is the responsibility of the local welfare authority, who would shoulder it if the epileptic were living in the community. This attempted dichotomy of function is, in the view of the Sub-Committee, unreal, and the attempted separation of welfare and treatment is in this field functionally impossible.

- (3) The management of the present colonies by means of voluntary committees allows of greater flexibility and opportunity for experiment and offers an opening for personal service. Yet an examination of the colonies does not suggest that these opportunities have been seized and, as the management and house committees of hospitals in the National Health Service have shown, there is ample opportunity for personal service.

59. It is our firm view that the best and most logical method of ensuring that the colonies will continue to make their special contribution and be enabled to play their optimal role in a unified national plan for the management of the epileptic is that they should ultimately be taken over by the Minister and be embodied in the National Health Service like other hospitals.

60. We recognise that legislation of this nature might present practical difficulties and would in any event be likely to take some time to come to fruition. Therefore, while we believe that the complete absorption of the colonies into the National Health Service is the best course, we think it wise to recommend other measures which could be taken in the interim period and would go some way towards securing the ends we have in view.

61. The most immediately practicable course would be to make contractual arrangements whereby Regional Hospital Boards and Boards of Governors could use the facilities of the colonies. We have in mind that for other purposes arrangements have been made by which Boards in whose area they are situated make payments to voluntary institutions for patients admitted through the Board, which also provides the necessary specialist staff; and this is the basis on which we consider that a very fruitful measure of functional integration between the work of the colonies and the remainder of the hospital service could be promoted. It may indeed, where goodwill is shown, prove temporarily a sufficient measure for full co-operation.

62. In more detail what we recommend is that, if necessary with the help of the Ministry of Health, arrangements should be made on the following lines between the colonies and the Regional Hospital Boards concerned:

- (1) Epileptic patients who have received all the benefit they can derive from the hospital diagnostic and treatment centres should be admitted to the colonies for longer-stay rehabilitation.
- (2) The specialist staff of the hospital centre should also act as the specialist staff of the colony and should be responsible, in collaboration with the medical staff of the colony, for determining the admission of patients to the colony, their rehabilitation while in it, and their discharge.
- (3) The appropriate Regional Hospital Board should be responsible for the cost of these patients while in the colony and for providing the specialist staff required.

63. We were very interested also in the arrangements which have recently been made between the Chalfont Colony and the National Hospital for Nervous Diseases. It is intended that all patients, either before or immediately after entering the Colony, should go into the hospital for full investigation and report; some, it is expected, will enter the hospital for treatment and will ultimately be discharged to normal life, while others will be admitted to the Colony, which will be given advice about their medical treatment. A Medical Advisory Committee consisting of members of the medical staff of the hospital has been appointed to advise the Colony on all matters relating to their patients, with particular reference to the neurological arrangements. This kind of structure may be paralleled at a new colony which, we understand, is about to be started at Leeds; here it is hoped that all new admissions and discharges will be effected in the closest liaison with the neurological clinic at the neighbouring hospital; and there will be close contact over all matters relating to treatment.

64. Arrangements of this general type, which seem to offer a satisfactory *interim* solution to the problem of associating the colonies with the National Health Service and ensuring that they play their full part in a national medical service for epileptics, should have as their objectives:

- (1) to ensure that the medical services for patients at colonies are adequate whether provided at the colony or at an associated hospital;
- (2) to encourage the colonies to play an active part in the field of rehabilitation;
- (3) to ensure that the colonies have satisfactory arrangements for the discharge, resettlement and "follow-up" of their patients.

65. We recommend that to secure these objectives serious consideration should be given to making arrangements on the lines described above between hospitals and colonies, if necessary with the help of the Ministry of Health.

Employment

66. We have already indicated in paragraph 40 that hospitals in our view should accept responsibility for helping to deal with the socio-economic problems of patients with epilepsy. Finding suitable employment is one of the most important of these. In some cases, as we have said, this will present little difficulty, but in others, where the disability is more severe, the problem will be much more acute, and it is these cases we now wish to deal with.

67. It may be helpful if we begin by referring briefly to the services which the Ministry of Labour and National Service provide for disabled persons, including epileptics, and to some of the difficulties which we understand they experience in trying to place epileptics in suitable employment.

68. Epileptics, like other classes of disabled persons, may benefit from the Ministry's rehabilitation, training and employment services and they may register as disabled persons under the Disabled Persons (Employment) Act, 1944, so long as they satisfy the conditions of eligibility laid down in the Act. These conditions provide that the disabled person must be capable of some form of remunerative employment (ordinary or sheltered) or work on his own account, but because of his disability is substantially handicapped in obtaining or keeping employment or in undertaking work on his own account of a kind which, apart from his disability, would be suited to his age, experience and qualifica-

tion. In suitable cases epileptics may be given a course of rehabilitation at one of the Ministry's industrial rehabilitation units and training under one of the Ministry's vocational training schemes. Epileptics who are on the register of disabled persons and are so severely disabled as to be unlikely to obtain ordinary employment may be considered for sheltered employment in a Remploy factory or other undertaking providing training and employment under sheltered conditions.

69. In addition to the normal guidance obtained through the usual medical channels (hospitals, regional medical service, etc.) to assist in the placing of disabled persons in suitable employment, a supplementary report is obtained wherever possible on epileptics showing the frequency and nature of fits, etc. Where, as is usually the case, an epileptic consents to the disclosure of his epileptic condition to prospective employers, a special approach is made by the Disablement Resettlement Officer to employers with suitable work to ascertain whether they would be willing to employ an epileptic. If they are willing the epileptic is submitted for consideration for employment with a statement that the applicant is understood to be an epileptic. We gather that in practice a special interview is sometimes arranged and that the Disablement Resettlement Officer accompanies the applicant to introduce him to the employer. This should be more general.

70. We understand from the Ministry of Labour and National Service that finding suitable jobs for epileptics is one of the most difficult tasks of Disablement Resettlement Officers. Amongst the chief problems are these:

- (a) The dislike shown by fellow workers for interruptions and upsets caused by epileptics having seizures at work, and the employer's loss through fall in production. We understand that the leaflet which is handed to prospective employers by the Disablement Resettlement Officer stresses the need for understanding and co-operation on the part of the epileptic's fellow workers if he is to settle down satisfactorily and that additional copies are, where necessary, provided for distribution to foremen and other employees.
- (b) Employers' fears of possible legal liability in case of accidents at work. We understand the Ministry has been advised that, provided employers take reasonable precautions, they need not fear any special liability for accidents to epileptics or other classes of disabled persons. The National Insurance (Industrial Injuries) Act, 1946, covers epileptics in the same way as all other workers.
- (c) Restrictions imposed by the nature of the disablement on the scope of suitable work; for example, unsuitable for all epileptics is work involving climbing, fire, the handling of detonators, fast-moving machinery; but agriculture, market gardening, upholstery, clerical and domestic duties and many factory and workshop jobs provide suitable employment. In view of the statutory position regarding the issue of licences, jobs involving driving motor vehicles should be avoided.
- (d) The need for accurate assessment of disability. Complete frankness with the employer regarding an epileptic's condition has been found by the Ministry to be practically essential to successful placing. Ground is lost with employers when a more severely affected epileptic is unwittingly

submitted for employment as being a mild case; and also when an epileptic having obtained employment without disclosing his condition causes a shock to the employer or to other workers on having a seizure at work.

71. The experience of the Ministry of Labour and National Service, as set out above, shows how important it is that the patient's disability should be accurately assessed. It is clear that this is necessary not only to ensure that he undertakes work which is within his capabilities but also because an employer may well refuse to offer employment to epileptics in future if one whom he has accepted proves to be more prone to fits than he had been led to expect. This attitude of mind is understandable and appears to be fairly general—the experience of the Ministry of Education is that the presence in a normal school of a child liable to suffer from epileptic seizures may cause very serious difficulties, leading possibly to the child's removal from the school, if the teacher of the class has not been warned, but that a discussion beforehand between the School Medical Officer and the teacher is likely to prevent any such trouble. It is important, therefore, that there should be good relations and close co-operation between general practitioners, hospitals and colonies on the one hand and Disablement Resettlement Officers on the other. Information given to the latter about a patient's disabilities and capabilities must be with the patient's concurrence and should be full and frank. No doubt many doctors and hospitals already recognise this, but in our view the matter is one to which all hospitals and other institutions concerned with epileptics should give their urgent attention.

72. When a patient has found suitable employment it by no means follows that his troubles are at an end. Particularly if he has been in a hospital or colony for some time, he may find it difficult to re-adjust himself to normal life and this may sometimes lead to a temporary worsening of his epileptic symptoms. We have already emphasised the importance of ensuring that all epileptics have continuous medical supervision; but in these cases where there may be particular difficulty, hospitals and colonies would do well to make special arrangements; these might take the form of a period of discharge "on trial" during which the patient would attend the hospital as an out-patient at short regular intervals—or whenever he felt the need—so that his condition would be under regular observation. During such a "trial" period, before the patient has completely adjusted himself to living an independent life and while he still needs fairly continuous medical supervision, it may be helpful if he can live in hostel accommodation associated with the hospital or colony. We understand that a successful scheme on these lines has been arranged by St. David's Hospital. Under this scheme, the patient is for a few months allowed to be employed while living in a special block within the hospital precincts. During this time he contributes towards the cost of his maintenance but, by saving part of his earnings, is able to leave hospital with a small bank balance.

73. It seems clear that finding suitable living accommodation is in some cases a serious problem for the epileptic who has just been discharged from a hospital or colony, particularly in the interim period when he is trying to adjust himself to normal life and, particularly in the larger towns, hostels provided by local welfare authorities may be the answer for such patients also. An unhappy

experience of being given notice to leave lodgings because of social difficulties might make all the difference between a successful re-adjustment and relapse.

Domiciliary services

74. At the present time, only very limited services are being provided by local health authorities under section 28 of the National Health Service Act, 1946, which enables them to make arrangements for the prevention of illness and for care and after-care, and by local welfare authorities under section 29 of the National Assistance Act, 1948, which empowers them to provide welfare services for people who are blind, deaf or dumb or otherwise handicapped (see paragraphs 19 and 21(b)). Such services would obviously be of value to many epileptics, and we hope that local authorities will expand them as quickly as possible and that hospitals will co-operate in ensuring that they are used to the best advantage.

SUMMARY OF RECOMMENDATIONS

- (1) Sufferers from epilepsy should be encouraged to secure treatment for their disability and to follow the medical advice they are given. (Paragraph 26(2).)
- (2) General practitioners should take an active interest in the problems of the epileptic and should, generally in conjunction with hospitals, be responsible for the long-term medical supervision of such patients. (Paragraphs 27-28.)
- (3) Hospital authorities should, on a regional basis, establish diagnostic and treatment clinics and long-stay treatment and rehabilitation centres. (Paragraph 33.)
- (4) Centres should be of two types, according to the patients' anticipated length of stay. (Paragraph 31.)
- (5) Hospital authorities should enlist the co-operation of general practitioners. (Paragraph 34.)
- (6) Three or four special investigatory clinics for epileptics with behaviour problems should be set up at convenient geographical centres. (Paragraph 39.)
- (7) Hospitals should help in dealing with the epileptic's socio-economic problems. (Paragraph 40.)
- (8) Hospitals should co-operate with all other agencies concerned with those problems, and should consider establishing "resettlement clinics." (Paragraph 41.)
- (9) Children suffering from epilepsy should as far as possible be educated at ordinary schools. (Paragraph 45(i).)
- (10) The greatest care must be taken that children are not unnecessarily "labelled" as epileptics. (Paragraph 45(ii).)
- (11) The decision to send a child suffering from epilepsy to a special school should be taken only after assessment at a hospital diagnostic clinic. (Paragraph 45(iii).)
- (12) The general practitioner should inform the School Medical Officer of any child with epilepsy who is about to attain school age and is to attend an ordinary school. (Paragraph 45(iii).)

- (13) When a special school is associated with an epileptic colony, it should as far as possible be kept separate from the rest of the colony. (Paragraph 45 (iv).)
- (14) When the educational requirements of a child with epilepsy are being assessed, the services of an educational psychologist should be available. (Paragraph 45(v).)
- (15) Long-stay hospital units should be established for epileptic children with exceptionally bad behaviour disorders. (Paragraph 45(vi).)
- (16) Where an epileptic patient requires long-term institutional care, the type of institution should be chosen in accordance with the nature of his major disability, which may or may not be epilepsy. (Paragraph 47.)
- (17) The functions of the epileptic colonies should be as much therapeutic as custodial; they should be concerned with the medical care, and also with the rehabilitation and return to normal life, of their patients. (Paragraphs 54-56.)
- (18) It would be desirable for the epileptic colonies to provide vocational training, and to pay an economic wage for the work done. (Paragraphs 55(b)-56.)
- (19) The epileptic colonies would be able to play their optimal role in a unified national plan for the management of the epileptic if they became by law a part of the National Health Service. (Paragraph 60.)
- (20) Failing legislation of this nature, informal arrangements should be made to secure the association of the epileptic colonies with the hospital service. (Paragraphs 60-66.)
- (21) Hospitals, epileptic colonies and general practitioners should always give the Disablement Resettlement Officer full and frank information about the disabilities and capabilities of an epileptic requiring employment. (Paragraph 71.)
- (22) Consideration should be given to establishing hostels for epileptics who are employed, but still need continuing supervision. (Paragraphs 72-73.)
- (23) The domiciliary services of local health and welfare authorities should be extended. (Paragraph 74.)

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